

# Living with Spina Bifida: A Glimpse for Prevention Campaign Partners



# About This Book

This booklet is intended to educate those who want to learn more about spina bifida. It is not meant to be used as an introduction to spina bifida.

Most people, even those interested in working to prevent spina bifida, don't understand the range of disabilities and the daily impact of spina bifida on the lives of the families affected. Initially, this booklet was designed to educate potential members of the National Task Force on Folic Acid. As the booklet unfolded, we became aware that the need for it was broader.

This booklet is meant not only to inform you about spina bifida, but also to impress upon you the importance of preventing the defect. We hope that it will motivate you to join in the prevention campaigns that have been or will be developed. The average total lifetime cost to society for each infant born with spina bifida is approximately \$636,000, while the total cost for many children with spina bifida is well above \$1,000,000. The money involved doesn't address the physical and emotional tolls upon the families affected. If spina bifida could be prevented in just one child, our efforts would be worthwhile!

**We thank the Buchieris for so  
graciously sharing their story  
and pictures with us!**

Meet the Buchieri family: Nancy, Joey, Mike, and Nicole. Nicole has a severe form of spina bifida, and Joey has a milder form of spina bifida.



## A Baby with Spina Bifida



Spina bifida happens very early after conception, often before a woman even knows that she is pregnant. The spine does not form properly, leaving an opening in the spine. The severity of spina bifida varies with the size of the opening in the spine and the place it occurs. Spina bifida can range from mild, with little or no noticeable disability, to severe, with limited movement and function.

Babies born with spina bifida might need to have many surgeries. The opening in the spine must be closed.

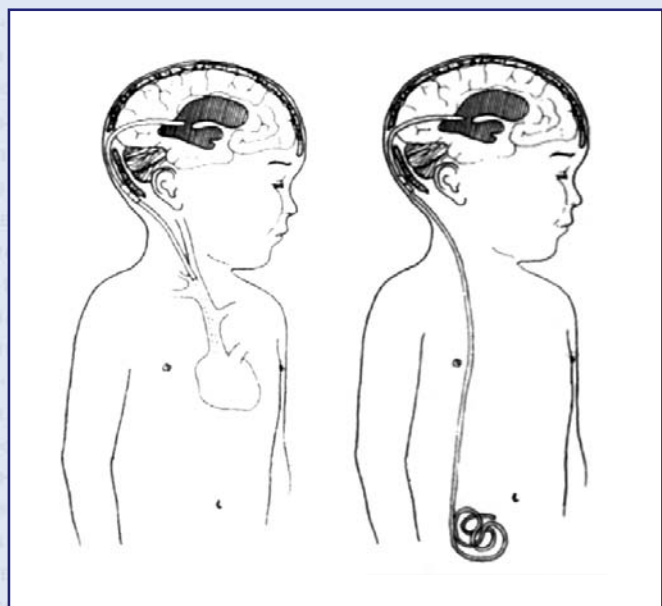


Nicole's scars are large.



Joey's scars are smaller.

Many babies with spina bifida develop hydrocephalus, also known as “water on the brain.” A baby with hydrocephalus must have a shunt inserted to reduce pressure on the brain. A shunt is a long tube placed inside the body that drains the extra fluid from the brain into the abdomen or the heart. Shunts need to be changed as the child grows and if they become clogged.



**Shunt to Heart**

**Shunt to Abdomen**

Most of these babies will grow into adulthood with different degrees of disabilities. These might include paralysis of the legs, lack of bowel and bladder control, and learning disabilities.

Joey, who has a milder form of spina bifida, can walk. However, he has to wear splints on his feet and legs all the time. Most people don't realize that Joey has spina bifida.



Nicole, who has a more severe form of spina bifida, is paralyzed. She moves about in her wheelchair.





Nicole is so severely affected that she doesn't swallow well. She must be fed through a gastrostomy tube (a tube through her skin into her stomach).

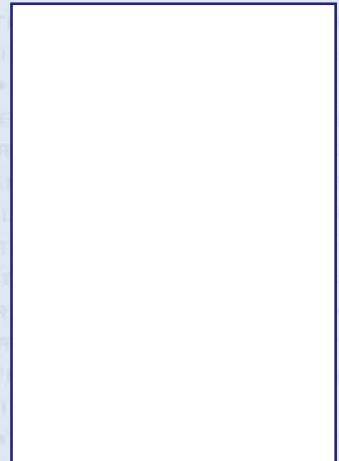


When Nicole sleeps, she receives oxygen through a mask to help keep her airway open.

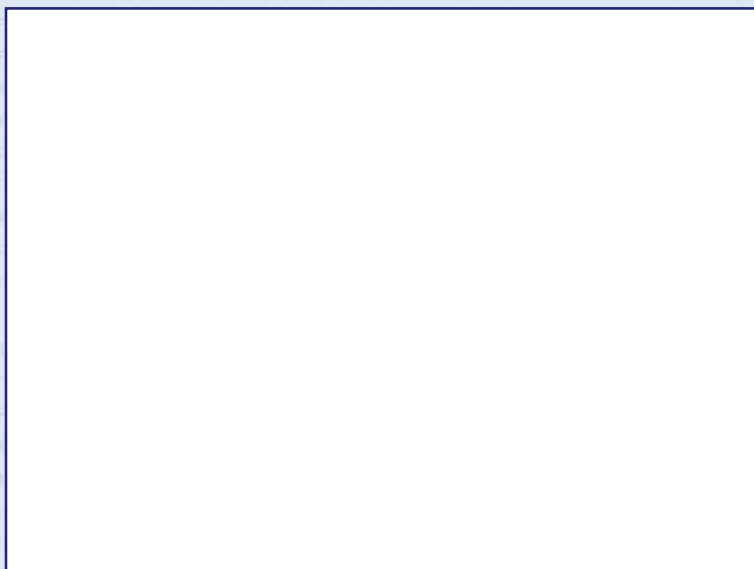
Joey and Nicole demonstrate the range of disabilities. Most children affected fall somewhere between. Some are able to get around with crutches and braces while others must use a wheelchair. Since shunts relieve pressure on the brain caused by hydrocephalus, mental retardation is rare. However, most affected children have some learning disability. Many of these children have problems with bowel and bladder control, a source of major concern and embarrassment to them.



Margaret, a friend, has moderate disabilities. She walks with the aid of braces and crutches most of the time. For long or physically demanding events, she uses a wheelchair.



The emotional and financial impact of these birth defects on families can be tremendous.



While it is difficult, some families adjust to the extra demands and function well.

The happy children pictured above are the result of the hard work, the dedication, and the love in the Buchieri family.

## A New Discovery

It is important to understand that having a child with spina bifida is no one's fault. About 95 percent of babies with spina bifida are born to parents who have no family history of spina bifida or related birth defects. A recent discovery tells us that women who take folic acid daily before and for a few months after conception have a much lower chance of having a baby with spina bifida. This is new information. Not everyone knows about it yet. However, even women who know about folic acid and take it daily can still have a baby with spina bifida.

The United States Public Health Service recommends the following to lower the chances of having a baby born with spina bifida:

1. All women of childbearing age who can become pregnant should take 400 micrograms (0.4 milligrams) folic acid every day. This is the usual amount found in one folic acid pill or in one multivitamin tablet or in one serving of fully fortified cereal. Look at the label to ensure getting 100% of the Daily Value (DV).
2. All women who have already had a child with spina bifida should take 4,000 micrograms (4 milligrams) of folic acid daily one month before planning another pregnancy and during the first few months of pregnancy. This dosage should be prescribed and monitored by a physician.

**For more information, contact :**

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